

Support
Re: HB 4584 . 5-17-17
Health Policy

Our Spina Bifida Story

Our story is unique, just like spina bifida.

Conner's story started at 12 weeks gestation. This is really early for most families to receive a diagnosis of a spinal bifida. We went in for our 12 week ultrasound and received the news that there was something wrong. There was something showing up on the spine, but because of how little he was we were referred to the Fetal Diagnostic Center at the University of Michigan. At our initial ultrasound our OB did not provide us with any information related to Spina Bifida, but made the choice to transfer care to the University of Michigan.

Once we transferred care to the University of Michigan that is when we received information about the potential outcome of what our son's life could be. We talked about his mobility, cognitive potential and lifelong health impacts that he may face. We were presented all factional options of how we could continue the pregnancy. Not once did the doctors state he was going to be a vegetable, never once did they tell us our son would not have a good quality of life.

We feel, my husband and I that the options that were presented to us were the best we could have obtained, luckily our OB knew where to send us and that allowed us to obtain the correct information. We have shared our story with other families, and friends that have passed the information along. Conner is far from the vegetable that we of heard many doctors describe. The decision to give factual and unbiased information to patients is crucial in our lives and the lives of others.

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